



END OF LIFE CARE BIBLIOGRAPHY

June 2004

1: Acad Med. 2004 May; 79(5):481-6.

End-of-life education using the dramatic arts: the Wit educational initiative.

Lorenz KA, Steckart MJ, Rosenfeld KE.

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Caring for dying persons requires skill in interpersonal aspects of care, which may be difficult to teach using conventional educational methods. The Pulitzer Prize-winning play Wit relates the personal story of a patient dying from metastatic ovarian cancer and describes the protagonist's experience with medical care from diagnosis to death. Members of the Department of Medicine at the VA Greater Los Angeles Health care System and the David Geffen School of Medicine, UCLA developed a program that utilized Wit to educate medical students, residents, and staff providers in the humanistic elements of end-of-life care. Between February 2000 and January 2002 the Wit Educational Initiative organized on-site readings of Wit by local professional theatre companies at medical centers throughout the United States and Canada, inviting medical students, housestaff, and other providers to attend the play followed by structured discussions of the play's themes. The Initiative provided extensive support for potential program sites including publicity, providing a handbook with a step-by-step guide to organizing local programs, and feedback of postperformance survey results. The Initiative was successful in organizing performances at 32 out of 54 (59%) medical centers where a local production of Wit was identified. Survey respondents confirmed the appeal, emotional impact, and perceived relevance of drama in end-of-life education. An educational program using theatre to educate trainees in the humanistic aspects of end-of-life care was enthusiastically received by medical schools and rated highly by attendees.

Publication Types:

Review

Review, Tutorial

PMID: 15107289 [PubMed - indexed for MEDLINE]

2: Age Ageing. 2004 Jan; 33(1):86; author reply 86-7.

Library Program Office
Office of Information
Veterans Health Administration

Comment on:

J Pediatr. 2003 Nov; 143(5):592-7.

Where now with Do Not Attempt Resuscitation decisions?

Elphick HL, Gott M, Liddle BJ.

Publication Types:

Comment

Letter

PMID: 14695876 [PubMed - indexed for MEDLINE]

3: Am J Geriatr Cardiol. 2004 Jan-Feb; 13(1):45-6.

Ethical issues in the management of geriatric cardiac patients.

Basta LL.

The University of South Florida, Tampa, FL, USA.

Publication Types:

Case Reports

PMID: 14724401 [PubMed - indexed for MEDLINE]

4: Am J Hosp Palliat Care. 2004 May-Jun; 21(3):209-15.

Joining forces, joining futures: hospice at the crossroads.

Pietroburgo J.

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Faced with health-policy changes, increased competition, and limited funding, hospices must either find more efficient ways to provide end-of-life care or risk organizational demise. Increasingly, hospices are re-evaluating their organizations to stretch resources and remain viable. Prevalent restructuring options for addressing environmental pressures are integration, alliance, and collaboration with other organizations. This study examines the restructuring phenomenon by evaluating trends among nonprofit hospices in six states. The study identifies demographic characteristics predictive of organizational decisions to join forces, and it examines the dominant political and economic reasons that propel or impede restructuring decisions. In addition, the study evaluates the results of restructuring actions.

PMID: 15188921 [PubMed - in process]

5: Am J Hosp Palliat Care. 2004 May-Jun;21(3):191-5.

Telehospice in Michigan: use and patient acceptance.

Whitten P, Doolittle G, Mackert M.

Department of Telecommunications, Michigan State University, East Lansing, Michigan, USA.

Telehospice, the use of telemedicine technologies to provide services to hospice patients, offers an innovative solution to the challenges of providing high-quality, cost-effective end-of-life care. Specifically, the technology allows caregivers to transmit video images of patients, which provide off-site nurses with the information they need to assist the caregiver. Our telehospice project was conducted in urban and rural Michigan between 2000-2002 and collected data from 187 patients receiving telehospice services in their homes during this study. Overall, nurses were the primary providers of telehospice services and initiated the majority of routine televisits. Often, patients who described themselves as "overwhelmed" at the time of enrollment declined telehospice. However, patients were extremely satisfied with telehospice and often expressed frustration that nurses did not use the telehospice equipment more frequently.

PMID: 15188918 [PubMed - in process]

6: Am J Med. 2004 May 15;116(10):669-75.

End-of-life care in a voluntary hospitalist model: effects on communication, processes of care, and patient symptoms.

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PURPOSE: To assess the effects of hospitalist care on communication, care patterns, and outcomes of dying patients. **METHODS:** We examined the charts of 148 patients who had died at a community-based, urban teaching hospital, comparing the end-of-life care provided by community physicians and hospitalists. **RESULTS:** Patients of hospitalists and community-based physicians were similar in age, race, severity of acute illness, and difficulties with activities of daily living. After admission, hospitalists had discussions with patients or their families regarding care more often than did community physicians (91% [67/74] vs. 73% [54/74], $P = 0.006$) and were more likely to document these discussions themselves. Among patients who were "full code" at admission, there was a trend towards patients of hospitalists receiving comfort care more frequently at the time of death (50% [25/48] vs. 37% [15/40], $P = 0.14$). Although there were no differences in the use of medications such as long-acting opioids, no symptoms in the 48 hours prior to death were more likely to be noted for patients of hospitalists (47% [$n = 35$] vs. 31% [$n = 23$]), $P = 0.03$). After adjustment for confounding factors in multivariable models, only findings regarding documentation of discussions and symptoms remained statistically significant. **CONCLUSION:** Hospitalists at a community-based teaching hospital documented substantial efforts to communicate with dying patients and their families, which

may have resulted in improved end-of-life care.

PMID: 15121493 [PubMed - indexed for MEDLINE]

7: Arch Gerontol Geriatr. 2004 Mar-Apr;38(2):123-30.

Measuring the suffering of end-stage dementia: reliability and validity of the Mini-Suffering State Examination.

Aminoff BZ, Purits E, Noy S, Adunsky A.

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Assessment of suffering is extremely important in dying end-stage dementia patients (ESDP). We have developed and examined the reliability and validity of the Mini-Suffering State Examination (MSSE), in 103 consecutive bedridden ESDP. Main outcome measures included inter-observer reliability and concurrent validity. Reliability of the MSSE questionnaire was satisfactory, with Cronbach alpha values of 0.735 and 0.718 for the two physicians (Ph-1, Ph-2), respectively. The kappa agreement coefficient was 0.791. There was a high agreement for seven items (kappa 0.882-0.972) and a substantial agreement for the other three items (kappa 0.621-0.682) of the MSSE. MSSE was validated versus the comfort assessment in dying with dementia (CAD-EOLD) scale and resulted in a significant Pearson correlation ($r=-0.796$, $P<0.001$). We conclude that the MSSE scale is a reliable and valid clinical tool, recommended for evaluating the severity of the patient's condition and the level of suffering of ESDP. Use of MSSE may improve medical management and facilitate communication between patients and caregivers.

Publication Types:

Validation Studies

PMID: 14698490 [PubMed - indexed for MEDLINE]

8: Arch Intern Med. 2004 Apr 26;164(8):916-7; author reply 917.

Comment on:

Arch Intern Med. 2003 Jul 28;163(14):1645-9.

Muslim and Jewish perspectives on inappropriate treatment at the end of life.

Alibhai SM, Gordon M.

Publication Types:

Comment

Letter

PMID: 15111383 [PubMed - indexed for MEDLINE]

9: Arch Intern Med. 2004 Apr 26;164(8):916; author reply 917.

Comment on:

Arch Intern Med. 2003 Jul 28;163(14):1645-9.

The patient's right to faith.

Handzo G, Jacobs MR.

Publication Types:

Comment

Letter

PMID: 15111382 [PubMed - indexed for MEDLINE]

10: Arch Intern Med. 2004 Apr 26;164(8):916; author reply 917.

Comment on:

Arch Intern Med. 2003 Jul 28;163(14):1645-9.

Religious conviction and decisions near the end of life.

Mobeireek A.

Publication Types:

Comment

Letter

PMID: 15111381 [PubMed - indexed for MEDLINE]

11: Arch Intern Med. 2004 Apr 12;164(7):776-83.

Do-not-resuscitate orders in patients hospitalized with acute myocardial infarction: the Worcester Heart Attack Study.

Jackson EA, Yarzebski JL, Goldberg RJ, Wheeler B, Gurwitz JH, Lessard DM, Bedell SE, Gore JM.

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BACKGROUND: Coronary heart disease is the leading cause of death in Americans. Despite increased interest in end-of-life care, data regarding the use of do-not-resuscitate (DNR) orders in acutely ill cardiac patients remain extremely limited. The objectives of this study were to describe use of DNR orders, treatment approaches, and hospital outcomes in patients with acute myocardial infarction. **METHODS:** The study sample consisted of 4621 residents hospitalized with acute myocardial infarction at all metropolitan Worcester, Mass, area hospitals in five 1-year periods from 1991 to 1999. **RESULTS:** Significant increases in the use of DNR orders were observed during the study decade (from 16% in 1991 to 25% in 1999). The elderly, women, and patients with previous

diabetes mellitus or stroke were more likely to have DNR orders. Patients with DNR orders were significantly less likely to be treated with effective cardiac medications, even if the DNR order occurred late in the hospital stay. Less than 1% of patients were noted to have DNR orders before hospital admission. Patients with DNR orders were significantly more likely to die during hospitalization than patients without DNR orders (44% vs 5%). CONCLUSIONS: The results of this community-wide study suggest increased use of DNR orders in patients hospitalized with acute myocardial infarction during the past decade. Use of certain cardiac therapies and hospital outcomes are different between patients with and without DNR orders. Further efforts are needed to characterize the use of DNR orders in patients with acute coronary disease.

PMID: 15078648 [PubMed - indexed for MEDLINE]

12: Arch Pediatr Adolesc Med. 2004 May;158(5):415-8.

Comment on:

Arch Pediatr Adolesc Med. 2004 May;158(5):430-5.

Perspectives on quality at the end of life.

Feudtner C.

Publication Types:

Comment

Editorial

PMID: 15123468 [PubMed - indexed for MEDLINE]

13: Bioethics. 2004 Apr;18(2):87-103.

Sharing death and dying: advance directives, autonomy and the family.

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This paper critically examines the liberal model of decision making for the terminally ill and contrasts it with the familial model that can be found in some Asian cultures. The contrast between the two models shows that the liberal model is excessively patient-centered, and misconceives and marginalises the role of the family in the decision making process. The paper argues that the familial model is correct in conceiving the last journey of one's life as a sharing process rather than a process of exercising one's prior or counterfactual choice, and concludes by suggesting a policy framework for the practice of familialism that can answer the liberal challenge that familialism cannot safeguard the patient from abuse and neglect.

PMID: 15146852 [PubMed - indexed for MEDLINE]

14: BMC Palliat Care. 2004 May 23;3(1):2.

Can a "good death" be made better? : A preliminary evaluation of a patient-centred quality improvement strategy for severely ill in-patients.

Powis JE, Etchells E, Martin DK, MacRae SK, Singer PA.

Background: Prior studies attempting to improve end of life care have focused on specific outcomes deemed important to healthcare providers, with disappointing results. Improvement may be best achieved by identifying concerns important to individual patients, communicating the patients' concerns to the treating medical team, and repeating the process frequently until all concerns are addressed. Our objective was to conduct a preliminary evaluation of this innovative patient-centred quality improvement strategy. Methods: Initial interviews elicited participants' ideas for improvement, which were then fed back to health care providers by the study investigator. A rapid-cycle change model ensured frequent reassessment and continued feedback. The study involved 36 seriously ill, hospitalized patients on teaching general medical inpatient units of a tertiary care hospital. The main outcome measure was participants' ratings of satisfaction within different domains of care on follow-up interviews. Results: The proportion of participants who rated various aspects of their care as "excellent" or "very good" on initial interview was 72% for overall care, 64% for symptom control, 66% for level of support and, 75% for discussions about life sustaining treatments. Patients and families identified many actionable steps for improvement such as; better control of pain and shortness of breath, better access to physicians and medical information, more help with activities of daily living, improving the patient's environment, and shorter waits for nursing care, diagnosis, and treatment. Following feedback to the clinical team, participants reported improvement in overall care (32%), symptom control (44%), and support (40%). Only a minority had further discussions about life sustaining treatments. Conclusion: A patient-centred approach using rapid-cycle change was feasible and shows promise for improving the quality of end-of-life care. It should be evaluated on a larger sample in a controlled trial.

PMID: 15154968 [PubMed - as supplied by publisher]

15: BMJ. 2004 May 15;328(7449):E296-7.

Variability in end of life care.

Meier DE.

Publication Types:
Editorial

PMID: 15142948 [PubMed - indexed for MEDLINE]

16: BMJ. 2004 May 15;328(7449):1202; author reply 1202.

Comment on:

Library Program Office
Office of Information
Veterans Health Administration

BMJ. 2004 Mar 13;328(7440):607.

Use of healthcare resources in the last six months of life: how doctors learn may explain results.

Bernacki RE.

Publication Types:
Comment
Letter

PMID: 15142940 [PubMed - indexed for MEDLINE]

17: BMJ. 2004 May 15;328(7449):1201; author reply 1202.

Comment on:
BMJ. 2004 Mar 13;328(7440):607.

Use of healthcare resources in the last six months of life: findings should be approached with caution outside United States.

Love T, Fahey T.

Publication Types:
Comment
Letter

PMID: 15142938 [PubMed - indexed for MEDLINE]

18: BMJ. 2004 May 8;328(7448):1088-9.

Assisted suicide.

Huxtable R.

Publication Types:
Editorial

PMID: 15130958 [PubMed - indexed for MEDLINE]

19: BMJ. 2004 May 1;328(7447):1035.

Living wills will have to specify treatments that patient is refusing.

Dyer C.

Publication Types:
News

PMID: 15117784 [PubMed - indexed for MEDLINE]

20: Camb Q Healthc Ethics. 2004 Winter;13(1):61-7.

"Medical friendships" in assisted dying.

Clark CC, Kimsma GK.

Institute for Social and Policy Studies, Yale University, USA.

PMID: 15045917 [PubMed - indexed for MEDLINE]

21: Caring. 2004 Mar;23(3):50.

Are hospices responsible for patients' co-morbidities?

[No authors listed]

PMID: 15085654 [PubMed - indexed for MEDLINE]

22: Caring. 2004 Mar;23(3):34-7.

Palliative care: the legal and regulatory requirements (Part II).

Raffa CA.

Life Sciences Department, Arent Fox Kinter Plotkin & Kahn, PLLC's New York, USA.
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PMID: 15085652 [PubMed - indexed for MEDLINE]

23: Clin Cardiol. 2004 Jan;27(1):23-8.

Need for hospice and palliative care services in patients with end-stage heart failure treated with intermittent infusion of inotropes.

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BACKGROUND: Hospice and palliative care programs to relieve suffering and optimize management of terminally ill patients have grown rapidly in the United States. However, there are no data on the need for these services among patients with end-stage heart failure receiving intermittent infusion of intravenous inotropes. HYPOTHESIS: The need for hospice and palliative care programs among patients in end-stage heart failure who receive intermittent infusion of inotropes is investigated. METHODS: The study included all stable patients with refractory heart failure symptoms treated with inotropes in our outpatient unit.

A total of 73 patients (65 +/- 12 years; left ventricular ejection fraction 22 +/- 9%; New York Heart Association class 3.6 +/- 0.4) were seen during a 49-month period. Of these, 35 patients (48%) met hospice or palliative care evaluation criteria upon referral but were offered, and accepted, the alternative of parenteral inotropes. In all, 1,737 individual outpatient treatment sessions were given, with a mean of 24 +/- 19 sessions per patient (range 5 to 118 sessions), representing a minimum of 9,948 h of inotrope therapy. RESULTS: A total of 18 (25%) patients died, 6 (8%) patients were withdrawn from the program (3 by their primary physicians and 3 because of significant travel limitations); 4 (5%) patients required continuous intravenous home therapy; and 44 (61%) patients were discharged with significant improvement in their heart failure symptoms. Only 7 of the 18 patients who died had received hospice or palliative care intervention, mainly for the sake of comfort and to ease the transition among family members. The rest of the patients were comfortable and had accepted the natural evolution of their disease; they were not interested in or did not require hospice or palliative care intervention. Of the patients discharged from the outpatient cardiac infusion unit, the interval free of heart failure symptoms after the final infusion treatment ranged from 201 to 489 days, with no need for hospitalization or emergency room visits. CONCLUSION: Our results demonstrate that intermittent infusion of intravenous inotropes can be safely administered and can improve symptoms in a significant number of patients, probably by slowing the natural progression of heart failure. Although the full clinical impact of inotrope therapy in an outpatient setting has not been fully defined, other nonhemodynamic-related benefits should be sought and investigated. Our results suggest that intermittent infusion of intravenous inotropes is one of the prominent variables that requires particular attention. In our experience, the institution of intermittent infusions of intravenous inotropes can, in fact, modify end-stage heart failure symptoms that, in most patients, are currently perceived to lead to a terminal event. Thus, appropriate use of intermittent infusion of intravenous inotropes may not only improve functional class and symptoms in a significant number of patients identified as terminal by their poor response to conventional therapy, but it may also facilitate better utilization of hospice and palliative care resources among patients with end-stage heart failure. Furthermore, the need for hospice and palliative care in patients with heart failure should be revisited in view of adjuvant treatment options such as intermittent infusion of intravenous inotropes.

Publication Types:

Clinical Trial

Randomized Controlled Trial

PMID: 14743852 [PubMed - indexed for MEDLINE]

24: Crit Care Clin. 2004 Jul;20(3):XIII-XIV.

End-of-Life Care.

Campbell ML, Curtis JR.

Palliative Care and Clinical Ethics, Detroit Receiving Hospital, 4201 St. Antoine, Detroit, MI 48201, USA.

Publication Types:

Library Program Office
Office of Information
Veterans Health Administration

Editorial

PMID: 15183219 [PubMed - in process]

25: Crit Care Clin. 2004 Jul;20(3):363-80.

Communicating about end-of-life care with patients and families in the intensive care unit.

Curtis JR.

Division of Pulmonary and Critical Care Medicine, University of Washington, Harborview Medical Center, Box 359762, 325 Ninth Avenue Seattle, WA 98104-2499, USA.

PMID: 15183208 [PubMed - in process]

26: Crit Care Med. 2004 May;32(5):1230-1.

Improving end-of-life care: targeting what we can.

Keenan SP.

Publication Types:
Editorial

PMID: 15190981 [PubMed - in process]

27: Crit Care Med. 2004 May;32(5):1141-8.

Evaluation of a standardized order form for the withdrawal of life support in the intensive care unit.

Treece PD, Engelberg RA, Crowley L, Chan JD, Rubenfeld GD, Steinberg KP, Curtis JR.

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OBJECTIVE: The intensive care unit remains a setting where death is common, and a large proportion of these deaths are preceded by withdrawal of life support. We describe a quality improvement project implementing and evaluating a "withdrawal of life support order form" to improve quality of end-of-life care in the intensive care unit. DESIGN: Before-after evaluation. SETTING: County-owned, university-operated, tertiary, level I trauma center. SUBJECTS: Subjects were 143 nurses and 61 physicians. INTERVENTIONS: We conducted a before-after evaluation of the order form's implementation. The order form has sections on preparations, sedation/analgesia, withdrawal of mechanical ventilation, and the principles of life support withdrawal. To evaluate the form, we surveyed intensive care unit clinicians regarding satisfaction with the

form, measured nurse-assessed quality of dying and death with a 14-item survey (scored 0 for worst possible death to 100 for best possible), and performed chart review to assess narcotic and benzodiazepine use and time from ventilator withdrawal to death. MEASUREMENTS AND MAIN RESULTS: We surveyed 143 nurses and

61 physicians about satisfaction with the form. Among nurses reporting that the form was used ($n = 73$), most (84%) reported that the order form was helpful and they were most satisfied with the sedation and mechanical ventilation sections. Almost all physicians found the form helpful (95%), and $> 70\%$ of physicians found three of the four sections helpful (sedation, mechanical ventilation, and preparations). We obtained quality of dying and death scores for 41 patient deaths before and 76 deaths after the intervention. These scores did not significantly change (mean preintervention score, 78.3; mean postintervention score, 74.2; $p = .54$) before and after the intervention. Total doses of narcotics and benzodiazepines increased after implementation of the order form in the hour before ventilator withdrawal, the hour after ventilator withdrawal, and the hour before death ($p < \text{or} = .03$). There was no change in the median time from ventilator withdrawal to death (preintervention 37 mins, postintervention 39 mins; $p = .49$). CONCLUSIONS: Nurses and physicians found the withdrawal of life support order form helpful. The order form did not improve nurses' assessment of patients' dying experience. Medications for sedation increased during the postorder form period without evidence of significantly hastening death. Although the order form was helpful to clinicians and changed medication delivery, demonstrating clear improvements in quality of dying may require larger sample sizes, more sensitive measures, or more effective interventions.

PMID: 15190964 [PubMed - in process]

28: Death Stud. 2004 May;28(4):289-308.

A perspective on the current state of death education.

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The author offers some views on the current state of death education with focus on the sparing attention given the death education of health professionals and of grief counselors. There is need for improved integration of the knowledge accumulated in the study of death, dying, and bereavement into the basic curricula of the parent disciplines and professional schools. Facilitation of personal engagement with the issue of mortality is an important component of the educative process. Various assessment problems are outlined and some suggestions for improvements are offered. The death education needs of various groups, including school age children and older adults, are noted. The article contains a list of references, many not cited in the text, recommended for an extensive review of developments in death education.

Publication Types:
Historical Article

PMID: 15129687 [PubMed - indexed for MEDLINE]

29: Dimens Crit Care Nurs. 2004 Mar-Apr; 23(2):89-92.

End-of-life Education in Undergraduate Nursing Curricula.

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Americans are increasingly dying in hospitals. The provision of end-of-life care is essential to providing a death with dignity. However, this is not taught in many schools of nursing. The purpose of this article is to discuss the importance of including this important content in nursing curricula.

PMID: 15192371 [PubMed - as supplied by publisher]

30: Fam Med. 2003 Oct; 35(9):637-42.

Unmet need for chronic disease and end-of-life care at urban family health centers in the Bronx, NY.

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BACKGROUND AND OBJECTIVES: With population demographic shifts and as people live

longer with progressive incurable illnesses, there will be a growing need for community-based chronic disease and end-of-life care services. Family practice sites could be strategic community-based settings in which to offer chronic disease and end-of-life care. This study determined whether two urban family health centers were meeting the chronic disease and end-of-life care needs of health center users, their families, and the local community. METHODS: Using a brief structured interview instrument, we interviewed a convenience sample of 218 patients at two hospital-affiliated family health centers in the Bronx, NY, about their recent experiences with serious illness and death of immediate family members. In addition, we developed geographically defined medical service areas for each health center and compared the age distribution of residents of the geographic areas with that of actual health center users. RESULTS: Of 218 health center users, 18% (n=39) had experienced the death of an immediate family member in the past year, of whom only 8% (n=3) stated that their family member had received end-of-life/chronic disease care at the health center, and only 23% (n=9) knew that their family member could have received such care. Of 26% (n=56) of study subjects who reported having an immediate family member who was currently seriously ill, 18% (n=10) stated that their family members were receiving care at the health center, and 23% (n=13) knew that their family members could have received such care. Eighty percent (n=174) of study subjects stated that they themselves would be interested in receiving end-of life/ chronic disease care at the health center in the event that they needed such

care. The age distribution of health center users significantly differed from that of the residents of the geographically defined medical service areas, with an underrepresentation of people over the age of 75 among the health center users. CONCLUSIONS: We identified a potential unmet need for chronic disease and end-of-life care among families of health center users and the larger community served by two family health centers in the Bronx, NY. Despite the frequent occurrence of serious illness and recent death among close family members, relatively small proportions of these family members had received care at the health centers, and few actual users were aware that such services could be provided there. Moreover, there was a significant demographic mismatch in age distribution between health center users and the surrounding community. These findings signal an important opportunity for the discipline of family medicine and its training programs to define and respond to the chronic disease and end-of-life care needs of patients and their families in community-based settings.

PMID: 14523661 [PubMed - indexed for MEDLINE]

31: Gerontologist. 2004 Apr;44(2):159-65.

Nursing facility compliance with do-not-hospitalize orders.

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PURPOSE: This study sought to determine whether nursing homes comply with residents' do-not-hospitalize (DNH) orders prohibiting inpatient hospitalization. DESIGN AND METHODS: With the use of data from the nationally representative 1996 Nursing Home Component of the Medical Expenditure Panel Survey, a multivariate logistic regression model was developed. RESULTS: Three percent of residents had DNH orders. These residents were half as likely to be hospitalized. Residents in not-for-profit or public facilities were less likely to be hospitalized than those in for-profit homes. Hospitalization was more likely among men, racial or ethnic minorities, those with more diagnosed health conditions, and those in facilities in the South compared with those in the Midwest. Hospitalized residents with DNH orders had no limitations of activities of daily living, were not located in hospital-based nursing homes, were less likely to be in a for-profit facility, and were sicker than nonhospitalized residents with DNH orders. IMPLICATIONS: Improved education regarding advance directives, particularly DNH orders, is necessary for health care practitioners and patients. More consistent and rigorous policies should be implemented in nursing facilities.

PMID: 15075412 [PubMed - indexed for MEDLINE]

32: Health Aff (Millwood). 2004 May-Jun;23(3):194-200.

Place of death: U.S. trends since 1980.

Flory J, Yinong YX, Gurol I, Levinsky N, Ash A, Emanuel E.

Library Program Office
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Place of death is one indicator of the state of end-of-life care. We examine trends in national death certificate data on place of death from 1980 to 1998. During these years the percentage of Americans dying as hospital inpatients decreased from approximately 54 percent to 41 percent. About 310,000 fewer people died in the hospital in 1998 than if the proportion of inpatient deaths had not changed since 1980. For certain diseases the change was much greater. In 1980 whites and African Americans died in the hospital in equal proportions, but in 1998 whites died as inpatients less often than African Americans. These racial differences and their implications deserve further study.

PMID: 15160817 [PubMed - in process]

33: Int J Palliat Nurs. 2004 Apr;10(4):202-3.

Reflections on the contribution of Frances Sheldon.

Payne S, Speck P.

Palliative and End-of-Life Care Research Group, University of Sheffield, Bartolome House, Winter Street, Sheffield S3 7ND, UK.

Publication Types:
Letter

PMID: 15150456 [PubMed - in process]

34: Int J Palliat Nurs. 2004 Mar;10(3):133-43.

The experience of family members caring for a dying loved one.

Perreault A, Fothergill-Bourbonnais F, Fiset V.

SCO Health Service, University of Ottawa Institute of Palliative Care, and C.A.R.M.E.N. Centre, 160 boul. de l'hôpital, suite 103, Gatineau, Quebec, Canada.

Qualitative nursing research into the experience of family members caring for a dying loved one has been limited. This study used a phenomenological approach to explore this experience. The pattern of caring for a dying loved one and its intertwined dimensions were described. Caregivers felt a sense of helplessness that was associated with illness progression, their inability to relieve pain and discomfort, and decision-making related to patient admission to a palliative care unit. Lack of support from health professionals and having to face personal limits were found to accelerate the decision to admit a patient. The role of a support person involved with the caregiver was also considered and found to be an area worthy of further investigation. Health professionals must provide information and support tailored to the caregivers' needs as they change along a patient's illness trajectory.

PMID: 15126958 [PubMed - indexed for MEDLINE]

35: Int J Palliat Nurs. 2004 Mar; 10(3):124-30.

Discharging patients from hospice to nursing home: a retrospective case note review.

Enes SP, Lucas CF, Aberdein N, Lucioni J.

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This article presents a retrospective case note review of in-patients at one UK hospice considered for discharge to nursing homes during 1999 and 2000. The idea of a nursing home placement was introduced, on average, around 9 days after admission to the hospice; the most common reason cited being the inability to cope at home. Nearly a third of the patients expressed negative or ambivalent feelings about the idea. Transferring patients from hospice to nursing home is often necessary to avoid pressures on hospice beds. The potential distress of transferring patients, particularly when nearing the end of life, must be balanced against the needs of patients on hospice waiting lists. Of the 41 cases reviewed, 16 were transferred to nursing homes as planned, with a mean length of stay of just over 8 weeks. The current provision of palliative care in nursing homes raises ethical questions about transferring patients to an unfamiliar environment that may not necessarily be able to offer the same quality of palliative care. Clear communication with patients and their families and a consistent process are important to reduce some of the distress associated with this issue.

PMID: 15126956 [PubMed - indexed for MEDLINE]

36: Int J Palliat Nurs. 2004 Mar; 10(3):123.

Comment in:

Int J Palliat Nurs. 2004 Mar; 10(3):108.

NICE supportive and palliative care guidance.

Payne S.

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PMID: 15126955 [PubMed - indexed for MEDLINE]

37: Intern Med J. 2003 Dec; 33(12):586-92.

Advance directives and emergency department patients: ownership rates and perceptions of use.

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BACKGROUND: Advance directives (ADs) are rarely available in Australia to guide management but may become more important as our population ages. **AIMS:** The present study aimed to determine patient knowledge, perception and ownership rates of ADs and the factors that impact upon these variables. **METHODS:** A cross-sectional survey of emergency department patients was undertaken. The main outcome measures were: (i) prior discussion about the extent of medical treatment and ADs, (ii) knowledge and perceptions of ADs, (iii) present AD ownership rates and (iv) likelihood of future AD ownership. Generalized linear models were used for analysis. **RESULTS:** Four hundred and three patients were enrolled. The mean age of patients was 73 years and 239 (59.3%) were male. Two hundred and forty patients (59.6%) had discussed the extent of treatment. Only 81 patients (20.1%) had discussed the use of an AD. One hundred and thirty-seven patients (34.0%) knew of one type of AD and 333 patients (82.6%) thought some ADs were a good idea. Only 32 patients (7.9%) owned an AD, although 276 (68.5%) would consider owning one. The main reason for never obtaining an AD was "always wanting full treatment" (93 patients, 23.1%). Level of education was the only characteristic that impacted significantly upon an outcome measure. Patients with a higher level of education were more likely to have known and spoken about ADs, to own an AD and to consider owning one. **CONCLUSIONS:** AD knowledge and ownership rates were low. However, most patients perceive them favourably and many would consider owning one. Intervention strategies to improve AD awareness are indicated. This may empower patients to more effectively participate in their own advance care planning.

PMID: 14656233 [PubMed - indexed for MEDLINE]

38: Intern Med J. 2003 Dec; 33(12):549-51.

Comment on:

Intern Med J. 2003 Dec; 33(12):566-71.

Haematology and palliative care: blood, sweat and tears.

Newton S.

Publication Types:

Comment

Editorial

PMID: 14656224 [PubMed - indexed for MEDLINE]

39: J Adv Nurs. 2004 Mar; 45(6):611-20.

Living with a terminal illness: patients' priorities.

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BACKGROUND: Our understanding of terminal illness and its consequences has been predominantly based on models derived from expert definition, rather than the patient's perspective. More recently, quality of life tools have been developed to enable patient choice in responses. However, an even broader approach may be needed to help identify goals for care for patients who are terminally ill. **AIM:** The aim of this paper is to report on an exploratory, qualitative study exploring what people living with terminal illness considered were the areas of priority in their lives. **METHODS:** Ten people living with terminal cancer were interviewed. Analysis of the interviews incorporated principles of narrative analysis and grounded theory. **FINDINGS:** Over 30 categories were identified and collated into five inter-related themes (personal/intrinsic factors, external/extrinsic factors, future issues, perceptions of normality and taking charge) encompassing the issues of importance to all participants. Each theme focused on 'life and living' in relation to life as it was or would be without illness. Practical issues of daily living and the opportunity to address philosophical issues around the meaning of life emerged as important areas. The central theme, 'taking charge', concerned with people's levels of life engagement, was integrally connected to all other themes. **CONCLUSIONS:** The findings suggest that the way in which health professionals manage patients' involvement in matters such as symptom relief can impact on existential areas of concern. Understanding patients' perspectives in relation to each theme may assist health professionals to develop management strategies appropriate to their needs. The findings challenge some aspects of traditional 'expert-defined' outcome measures. As this was an exploratory study, further work is needed to test and develop the model presented.

PMID: 15012639 [PubMed - indexed for MEDLINE]

40: J Am Coll Surg. 2004 May;198(5):837-41.

Terminal care in head and neck cancer patients: a framework for medical decision making.

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Publication Types:

Case Reports

Review

Review, Tutorial

PMID: 15110819 [PubMed - indexed for MEDLINE]

41: J Am Geriatr Soc. 2004 Jun;52(6):1027-8.

End-of-Life Care and Family Involvement.

Iraqi AH, Hughes TL.

Library Program Office
Office of Information
Veterans Health Administration

PMID: 15161479 [PubMed - in process]

42: J Am Geriatr Soc. 2004 May;52(5):850; author reply 850-1.

Comment on:

J Am Geriatr Soc. 2002 Dec;50(12):2057-61.

Unilateral limitation of treatment by physicians?

Gillick MR.

Publication Types:

Comment

Letter

PMID: 15086683 [PubMed - indexed for MEDLINE]

43: J Am Geriatr Soc. 2004 May;52(5):736-40.

Differences in end-of-life preferences between congestive heart failure and dementia in a medical house calls program.

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OBJECTIVES: To compare end-of-life preferences in elderly individuals with dementia and congestive heart failure (CHF). **DESIGN:** Retrospective case-control study. **SETTING:** Geriatrician-led interdisciplinary house-call program using an electronic medical record. **PARTICIPANTS:** Homebound individuals who died while under the care of the house-call program from October 1996 to April 2001. **MEASUREMENTS:** Medical records review for demographics, functional status, advance medical planning, hospice use, and place of death. **RESULTS:** Of 172 patients who died in the program, 29 had CHF, 79 had dementia, 34 had both, and 30 had neither. Patients with CHF were younger (82.6 vs 87.0, $P=.011$) and less functionally dependent (activities of daily living score 9.1 vs 11.5, $P=.001$). Time from enrollment to death was not significantly different (mean \pm standard deviation=444 \pm 375 days for CHF vs 325 \pm 330 days for dementia, $P=.113$). A do-not-resuscitate (DNR) directive was given in 62% of patients with CHF and 91% with dementia ($P<.001$). Advance medical planning discussions were not significantly different (2.10 in CHF vs 1.65 in dementia, $P=.100$). More patients with CHF participated in their advance medical planning than those with dementia (86% vs 17%, $P<.001$). Hospice was used in 24% of CHF and 61% of dementia cases ($P<.001$). Finally, 45% of patients with CHF and 18% of patients with dementia died in the acute hospital ($P=.006$). Multivariate analysis showed that the fact that more patients with CHF were involved in their medical planning was not significant in predicting end-of-life preferences. Alternatively, Caucasian ethnicity was an independent predictor of having a documented DNR and death outside of the acute hospital. **CONCLUSION:** In the months before death, patients with CHF were more likely to have care plans directed at disease modification

and treatment, whereas dementia patients were more likely to have care plans that focused on symptom relief and anticipation of dying. Several factors may contribute to this difference.

PMID: 15086654 [PubMed - indexed for MEDLINE]

44: J Am Geriatr Soc. 2004 May;52(5):731-5.

Do rural elders have limited access to Medicare hospice services?

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OBJECTIVES: To examine whether there are urban-rural differences in use of the Medicare hospice benefit before death and whether those differences suggest that there is a problem with access to hospice care for rural Medicare beneficiaries. **DESIGN:** Observational study using 100% of Medicare enrollment, hospice, and hospital claims data. **SETTING:** Inpatient hospitals and hospices. **PARTICIPANTS:** Persons aged 65 and older in the Medicare program who died in 1999. **MEASUREMENTS:** Rates of hospice use before death and in-hospital death rates were calculated. **RESULTS:** In 1999, there were 1.76 million deaths of Medicare beneficiaries aged 65 and older. Hospice services were used by 365,700 of these beneficiaries. Rates of hospice care before death were negatively associated with degree of rurality. The lowest rate of hospice use, 15.2% of deaths, was seen in rural areas not adjacent to an urban area. The highest rate of use, 22.2% of deaths, was seen in urban areas. Rural areas adjacent to urban areas had an intermediate level of hospice use (17.0% of deaths). Hospices based in rural areas had a smaller number of elderly patients each year than hospices based in urban areas ($P < .001$) and were more likely to have very low volumes (average daily census of three patients or less). **CONCLUSION:** The consistently lower use of Medicare hospice services before death and smaller sizes of rural hospices suggest that the combination of Medicare hospice payment policies and hospice volumes are problematic for rural hospices. Adjusting Medicare payment policies might be a critical step to assure availability of hospice services for terminally ill beneficiaries regardless of where they live.

PMID: 15086653 [PubMed - indexed for MEDLINE]

45: J Am Geriatr Soc. 2004 May;52(5):725-30.

Hospice admission practices: where does hospice fit in the continuum of care?

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OBJECTIVES: To evaluate selected hospice admission practices that could represent barriers to hospice use and the association between these admission practices and organizational characteristics. **DESIGN:** From December 1999 to

March 2000, hospices were surveyed about selected admission practices, and their responses were linked to the 1999 California Office of Statewide Health Planning and Development's Home and Hospice Care Survey that describes organizational characteristics of California hospices. SETTING: California statewide. PARTICIPANTS: One hundred of 149 (67%) operational licensed hospices. MEASUREMENTS: Whether hospices admit patients who lack a caregiver; would not forgo hospital admissions; or are receiving total parenteral nutrition (TPN), tube feedings, radiotherapy, chemotherapy, or transfusions. RESULTS: Sixty-three percent of hospices restricted admission on at least one criterion. A significant minority of hospices would not admit patients lacking a caregiver (26%). Patients unwilling to forgo hospitalization could not be admitted to 29% of hospices. Receipt of complex medical care, including TPN (38%), tube feedings (3%), transfusions (25%), radiotherapy (36%), and chemotherapy (48%), precluded admission. Larger program size was significantly associated with a lower likelihood of all admission practices except restricting the admission of patients receiving TPN or tube feedings. Hospice programs that were part of a hospice chain were less likely to restrict the admission of patients using TPN, radiotherapy, or chemotherapy than were freestanding programs. CONCLUSION: Patients who are receiving complex palliative treatments could face barriers to hospice enrollment. Policy makers should consider the clinical capacity of hospice providers in efforts to improve access to palliative care and more closely incorporate palliation with other healthcare services.

PMID: 15086652 [PubMed - indexed for MEDLINE]

46: J Am Geriatr Soc. 2004 Apr;52(4):641-2.

Comment on:

J Am Geriatr Soc. 2004 Apr;52(4):577-82.

Advance directives and advancing age.

Emanuel LL.

Publication Types:

- Comment
- Editorial
- Review
- Review, Tutorial

PMID: 15066087 [PubMed - indexed for MEDLINE]

47: J Am Geriatr Soc. 2004 Apr;52(4):577-82.

Comment in:

J Am Geriatr Soc. 2004 Apr;52(4):641-2.

Physical functioning, depression, and preferences for treatment at the end of life: the Johns Hopkins Precursors Study.

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OBJECTIVES: To examine the relationship between worsening physical function and depression and preferences for life-sustaining treatment. **DESIGN:** Mailed survey of older physicians. **SETTING:** Longitudinal cohort study of medical students in the graduating classes from 1948 to 1964 at Johns Hopkins University. **PARTICIPANTS:** Physicians who completed the life-sustaining treatment questionnaire in 1998 and provided information about health status in 1992 and 1998 (n=645, 83% of respondents to the 1998 questionnaire; mean age 68). **MEASUREMENTS:** Preferences for life-sustaining treatment, assessed using a checklist questionnaire in response to a standard vignette. **RESULTS:** Of 645 physicians, 11% experienced clinically significant decline in physical functioning, and 18% experienced worsening depression over the 6-year period. Physicians with clinically significant functional decline were more likely (adjusted odds ratio (AOR)=2.14, 95% confidence interval (CI)=1.18-3.88) to prefer high-burden life-sustaining treatment. Worsening depression substantially modified the association between declining functioning and treatment preferences. Physicians with declining functioning and worsening depression were more likely (AOR=5.33, 95% CI=1.60-17.8) to prefer high-burden treatment than respondents without declining function or worsening depression. **CONCLUSION:** This study calls attention to the need for clinical reassessment of preferences for potentially life-sustaining treatment when health has declined to prevent underestimating the preferences of older patients.

PMID: 15066074 [PubMed - indexed for MEDLINE]

48: J Am Geriatr Soc. 2004 Apr;52(4):532-9.

Out-of-hospital death: advance care planning, decedent symptoms, and caregiver burden.

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OBJECTIVES: To examine the end-of-life experiences of elderly decedents dying out of the hospital and their family caregivers in a state in which the vast majority of Medicare deaths occur in community settings. **DESIGN:** Telephone survey of family caregivers 2 to 5 months after decedents' deaths. **SETTING:** Statewide (Oregon) random sample of death certificates. **PARTICIPANTS:** One thousand one hundred eighty-nine family caregivers of decedents aged 65 and older who died of natural deaths in community settings between 2000 and 2002. **MEASUREMENTS:** A 69-item telephone questionnaire with single-item indicators and embedded scales that indexed advance directives, use of life-sustaining treatments, hospice enrollment, decedent symptom experience and perceived distress, family financial hardship, out-of-pocket expenses, and caregiver strain. **RESULTS:** Most decedents had advance directives (78.3%) and were enrolled in hospice (62.4%). Although perceived decedent symptom distress was low overall, certain symptoms (e.g., pain, dyspnea, constipation) were distressing for approximately half of decedents experiencing them. Financial hardship, out-of-pocket expenses, and caregiver strain were frequently reported. American

Indian race and younger age were associated with decedent symptom distress. Greater perceived decedent symptom distress, hospice enrollment, more caregiver involvement, and more financial burden were associated with greater caregiver strain. CONCLUSION: Despite high rates of advance directives and hospice enrollment, perceived symptom distress was high for a subset of decedents, and caregiver strain was common. As location of death increasingly shifts nationwide from hospital to community, unmet decedent and family needs require new clinical skills and healthcare policies.

PMID: 15066067 [PubMed - indexed for MEDLINE]

49: J Clin Oncol. 2004 May 15;22(10):1966-74. Epub 2004 Apr 26.

Are chemotherapy response rates related to treatment-induced survival prolongations in patients with advanced cancer?

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PURPOSE: Patients with incurable cancer are faced with difficult decisions regarding whether to take chemotherapy in an attempt to preserve the quality and/or prolong the quantity of their lives. The average prolongation in survival with chemotherapy compared with best supportive care has not been well described. METHODS: We performed a literature search using PUBMED combined with expert inquiry to identify trials comparing cytotoxic chemotherapy with best supportive care. Twenty-five randomized, controlled clinical trials comparing cytotoxic chemotherapy with best supportive care were identified. Sixteen trials (64%) were in patients with non-small-cell lung cancer (NSCLC). Data were extracted and analyzed. RESULTS: Sufficient data for statistical modeling were available for NSCLC trials. The mean sample size of the NSCLC trials was 175 patients. Response rates in the treatment arms for NSCLC ranged from 7% to 42%. A relationship between response rate and survival was observed for NSCLC. The estimated relationship for NSCLC suggested that each 3.3% increase in response rate correlated, on average, with a 1-week increase in median survival, and each 2% increase in response rate correlated, on average, with a 1% increase in 1-year survival. The mean increase in 1-year survival for trials of agents with at least a 20% response rate in NSCLC was 16%. Formulas are provided to help estimate how a given response rate may effect median and 1-year survival relative to best supportive care alone for NSCLC. CONCLUSION: We found a relationship between response rate and both median and 1-year survival in NSCLC. This information may help oncologists estimate how an NSCLC chemotherapy regimen with a given response rate can, on average, impact survival relative to supportive care alone.

PMID: 15111619 [PubMed - indexed for MEDLINE]

50: J Infus Nurs. 2004 Mar-Apr;27(2):112-7.

Infusion nurses' role in care at the end of life.

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End-of-life care has received focused attention over the past two decades in the United States. Although end-of-life care has greatly improved, considerable work remains to ensure that all Americans who are dying receive high-quality care. This important work cannot be delegated to one specialty area, but is the responsibility of all specialty nurses interacting with individuals who have life-limiting illnesses. Infusion nurses, in particular, are encouraged to commit themselves to ensuring the provision of high-quality end-of-life nursing care.

PMID: 15085038 [PubMed - indexed for MEDLINE]

51: J Pain Palliat Care Pharmacother. 2004;18(1):87-109.

Advance care planning: preferences for care at the end of life.

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Predictors of patient wishes and influence of family and clinicians are discussed. Research findings on patient decision-making relating to preferences in end-of-life care are described. Advance directives and durable powers of attorney are defined and differentiated. Most patients have not participated in advance care planning and the need for more effective planning is documented. Appropriate times for discussions of such planning are described. Scenarios discussed include terminal cancer, chronic obstructive pulmonary disease, AIDS, stroke, and dementia. Patient satisfaction is discussed, as is a structured process for discussions about patient preferences. Results of patient responses to hypothetical scenarios are described. Invasiveness of interventions, prognosis and other factors that favor or discourage patient preferences for treatment are discussed. Findings resulting from research funded by the Agency for Healthcare Research and Quality (AHRQ) are discussed. This research can help providers offer end-of-life care based on preferences held by the majority of patients under similar circumstances.

PMID: 15148012 [PubMed - in process]

52: J Pain Symptom Manage. 2004 Jun;27(6):492-501.

Measuring the quality of structure and process in end-of-life care from the bereaved family perspective.

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Measurement of the structure/process of care is the first step in improving end-of-life care. The primary aim of this study was to psychometrically validate an instrument for directly measuring the bereaved family's perception of the necessity for improvement in structural/procedural aspects of palliative care. Different sets of questionnaires were sent to 800 and 425 families who lost family members at one of 70 certified palliative care units in Japan in the development and validation phases, respectively, and 281 families of the latter group in the follow-up phase. The participants were requested to fill out a newly-developed Care Evaluation Scale (CES), along with outcome measures (the perceived experience and satisfaction levels) and potential covariates (the degree of expectation, the Center for Epidemiologic Studies Depression Scale, and the Social Desirability Scale). We obtained 485, 310, and 202 responses in the development, validation, and follow-up phases (response rates: 64%, 75%, and 72%, respectively). The 28-item CES had an overall Cronbach's coefficient alpha of 0.98; the intra-class correlation coefficient in the test-retest examination was 0.57. A confirmatory factor analysis revealed 10 subscales: physical care (by physicians, by nurses), psycho-existential care, help with decision-making (for patients, for family), environment, family burden, cost, availability, and coordination/consistency. The CES subscales were only moderately correlated with the perceived-experience and satisfaction levels of corresponding areas ($r=0.36-0.52$ and $0.39-0.60$, respectively). The CES score was not significantly associated with the degree of expectation, the changes of depression, or the Social Desirability Scale. The CES is a useful tool to measure the bereaved family's perception of the necessity for improvement in structural/procedural aspects of palliative care. The advantages of the CES are: 1) it specifically evaluates the structure and process of care, 2) it directly identifies needed improvements, 3) it is not affected by the degree of expectation, depression, or social desirability, and 4) it has satisfactory psychometric properties.

PMID: 15165647 [PubMed - as supplied by publisher]

53: J Pain Symptom Manage. 2004 Feb;27(2):125-32.

End-of-life care in urban areas of China: a survey of 60 oncology clinicians.

Wang XS, Di LJ, Reyes-Gibby CC, Guo H, Liu SJ, Cleeland CS.

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Although cancer is a leading cause of death, little is known about cancer-related end-of-life care in China. We surveyed 60 Chinese oncology clinicians' practices and attitudes toward end-of-life care. Fewer than half reported available hospital-based hospice service, although most urban cancer patients die in the hospital. Most clinicians reported they felt competent to care for dying patients--more competent in controlling pain, constipation, nausea, and vomiting, but less competent in managing depression, anorexia, and dyspnea. Regarding disclosure, most believed that patients should know and want

to know their diagnosis and stage, whereas families strongly resist informing patients. Unrealistic family expectations, fears of depressing patients, and physician reluctance to stop treatment were barriers to disclosing prognosis to patients, to ending anti-cancer therapy, and to starting palliative care. Results of the survey suggest specific training and research in symptom management that might improve end-of-life care for Chinese cancer patients.

PMID: 15157036 [PubMed - in process]

54: J Palliat Care. 2004 Spring;20(1):38-43.

Factors associated with caregiver burden among caregivers of terminally ill patients with cancer.

Goldstein NE, Concato J, Fried TR, Kasl SV, Johnson-Hurzeler R, Bradley EH.

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OBJECTIVE: To identify factors associated with caregiver burden among those caring for terminally ill patients with cancer. **DESIGN:** Cross-sectional study of interviews with primary caregivers (n = 206) of consecutive patients with cancer enrolled in the largest hospice in Connecticut. **METHODS:** Data were collected on the caregivers' sociodemographic characteristics, social network index, and number of restrictions in their own activities due to their caregiving role. The outcome was a nine-item questionnaire adapted from the Zarit Burden Inventory. **RESULTS:** The highest burden was reported among caregivers with more limited social networks (OR 1.38, CI 1.02-1.87), more restrictions in their daily activities (OR 1.35, CI 1.13-1.61), and who were younger (OR 1.46, CI 1.10-1.93). **CONCLUSIONS:** Variations exist in the intensity of caregiver burden based on subjective experiences and social support, rather than on the amount of assistance provided. Clinicians should consider factors such as these when targeting caregivers for interventions to alleviate burden.

PMID: 15132075 [PubMed - indexed for MEDLINE]

55: J Palliat Care. 2004 Spring;20(1):20-7.

Family perceptions of worry, symptoms, and suffering in the dying.

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In this exploratory study, family members of 63 decedents were interviewed by telephone, two to five months post-death, about their perceptions of their loved one's worries, symptoms, and suffering at the end of life. The most common worries reported focused on loss of bodily function (44%), being dependent (40%), and being a burden (39%). Distressing physical and psychological symptoms were reported. A majority (94%) of family members reported that their loved one suffered at the end of life, but only worries about loss of quality of life

(e.g., being unable to participate in enjoyable activities) were predictive of reports of suffering. Findings suggest that worries, irrespective of the level of current symptoms, play an important role in the suffering of dying patients, and that treatment plans for the terminally ill should routinely explore both symptoms and worries.

PMID: 15132072 [PubMed - indexed for MEDLINE]

56: J Palliat Care. 2004 Spring;20(1):7-11.

The nature of suffering and its relief in the terminally ill: a qualitative study.

Daneault S, Lussier V, Mongeau S, Paille P, Hudon E, Dion D, Yelle L.

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The essential mandate of medicine is the relief of suffering. However, the quest for an integrated model towards a conceptualization of suffering is still ongoing and empirical studies are few. Qualitative inquiry using 31 in-depth interviews and content analysis was carried out between 1999 and 2001 in 26 patients diagnosed with terminal cancer. The suffering experience was described through a multiplicity of heterogeneous elements from the physical, psychological, and social spheres. Systematic synthesis of interview material yielded three apparently irreducible core dimensions. Respondents defined their suffering in terms of 1) being subjected to violence, 2) being deprived and/or overwhelmed, and 3) living in apprehension. Cassell wrote, in 1991, that to know the suffering of others demands an exhaustive understanding of what makes them the individuals they are (1). Our model can be of use in structuring and eliciting this necessary information. Understanding how a particular patient feels harmed, deprived or overburdened, and overtaken by fear, provides a lever for action tailored to the specifics of that person's experience.

PMID: 15132070 [PubMed - indexed for MEDLINE]

57: J Palliat Care. 2004 Spring;20(1):5-6.

The Canadian Virtual Hospice <www.virtualhospice.ca>.

Chochinov HM, Stern A.

Publication Types:
Editorial

PMID: 15132069 [PubMed - indexed for MEDLINE]

58: J Palliat Med. 2004 Feb;7(1):19-25.

Meeting the supportive needs of family caregivers in palliative care: challenges

for health professionals.

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Caring for a dying relative is demanding, and family caregivers have acknowledged many unmet needs associated with their caregiver role. Consistently, caregivers of dying patients with cancer have reported that they need more support and information from health care professionals. Moreover, a number of palliative care clinicians and researchers have called for interventions to enhance the support offered to family caregivers. However, before researchers can develop and test palliative care interventions directed to families, it is important to identify barriers that may confront health care professionals with regard to the provision of supportive family care. For new interventions to be feasible they must be applicable within the constraints of current palliative care service delivery environments. This paper provides an account of issues that may impinge on optimal transference of supportive strategies from health care professionals to family caregivers of patients receiving palliative care. By acknowledging these barriers to supportive care, researchers and health care professionals can begin to design and implement interventions that are clinically relevant and more likely to be effective.

Publication Types:

Review

Review, Tutorial

PMID: 15008126 [PubMed - indexed for MEDLINE]

59: J Palliat Med. 2004 Feb;7(1):135-43.

Palliative care in the Pueblo of Zuni.

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The American Indian and Alaska Native population is aging and the leading causes of death for those aged 55 and older are chronic diseases such as cancer, heart disease, and the complications of diabetes. There are limited formal palliative care services available to rural and reservation dwelling American Indians and Alaska Natives. This collaboration between a tribally operated home health care agency and a federally operated Indian Health Service hospital, with the support of a palliative care center within an academic medical center, has established a palliative care program in the Pueblo of Zuni. The program is based in the tribal home health agency. Barriers to development included the rural setting with limited professional workforce, competing demands in a small agency, the need for coordination across distinct organizations, and the need to address the dying process in a culturally proficient manner. Family-focused interviews and other techniques were used to tailor the palliative care program to the unique cultural setting. The program has sought to integrate inpatient care of terminally ill patients at the Indian Health Service (IHS) hospital with outpatient hospice care. The initial goal of obtaining certification as a

Medicare Hospice provider has not been met and remains a goal. Meanwhile alternative mechanisms for funding the services have been found. The experience of this collaboration suggests that a tribally based, culturally proficient palliative care program can be developed within an American Indian/Alaska Native community and that it can drive the local health system toward improved end-of-life care.

PMID: 15000797 [PubMed - indexed for MEDLINE]

60: J Palliat Med. 2004 Feb;7(1):80-4.

Death pronouncements: using the teachable moment in end-of-life care residency training.

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INTRODUCTION: Performing death pronouncement and communicating effectively with gathered family is an important skill relevant to end-of-life care. Often it is a responsibility of first-year residents who lack proper training or emotional preparation for the task. Residents' tension about this task presents an opportunity to positively effect their emotions and build skills for providing end of life care in the future. This paper describes a death pronouncement workshop including its objectives specific to Accreditation Council on Graduate Medical Education (ACGME) competencies, its format and its evolution over 8 years. **METHODS:** Multiple media and methods are used in the 90-minute workshop for first-year family practice residents including poetry, prose, and narratives on doing death pronouncements by senior residents; reviews and discussion of protocols for death pronouncement, autopsy, and organ donation; and a role-play of a death pronouncement with the opportunity for reflection. **RESULTS:** Residents consistently provide high ratings for the overall value of workshop. **CONCLUSIONS:** The death pronouncement workshop serves to prepare residents emotionally to deal with dying patients and provides them the skills to effectively and compassionately communicate with those patients' families while addressing all six ACGME core competencies.

PMID: 15000790 [PubMed - indexed for MEDLINE]

61: J Palliat Med. 2004 Feb;7(1):77-8.

Not always a happy ending: the complexities of the doctor-patient relationship in end-of life care.

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PMID: 15000788 [PubMed - indexed for MEDLINE]

62: J Palliat Med. 2004 Feb;7(1):55-62.

An end-of-life curriculum: empowering the resident, patient, and family.

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Physician training programs in undergraduate and graduate medical education strongly recommend that their trainees gain experience in helping patients and their families address end-of-life and palliative care issues with knowledge and compassion. Currently these training programs are inadequately meeting this goal. This paper describes a creative 1-day training workshop or several half-day seminars on the end of life, which are delivered as part of our family practice intern orientation. The training includes self-awareness about death, communicating bad news, guidance with paperwork and legal issues, the stages of grief, patient's perspectives on dying, hospice, and physician well-being.

PMID: 15000783 [PubMed - indexed for MEDLINE]

63: J Palliat Med. 2004 Feb;7(1):47-53.

Medicare hospice referral criteria for patients with amyotrophic lateral sclerosis: a need for improvement.

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We conducted a retrospective review of 97 consecutive patients with amyotrophic lateral sclerosis (ALS) who were accepted into hospice care from a tertiary ALS center. Five patients met Medicare criteria at time of hospice enrollment. The mean number of hospice days was 85 (range, 1-534). All but 2 patients met hospice criteria proposed by the Columbia University ALS group. The present Medicare hospice criteria should be changed to reflect the reality of patients dying of ALS.

PMID: 15000782 [PubMed - indexed for MEDLINE]

64: J Palliat Med. 2004 Feb;7(1):39-45.

Trends in opioid use over time: 1997 to 1999.

Tolle SW, Hickman SE, Tilden VP, Bubalo JS, Fromme EK.

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Substantial resources have been spent to improve pain control for dying patients, and increased opioid administration has been presumed. Oregon has been a consistent leading state in per capita use for morphine for the past 10 years, as recorded by the Automation of Reports and Consolidated Orders System (ARCOS). Health policy experts, extrapolating from World Health Organization methods, have suggested these data are indicative of the quality of end-of-life care in Oregon. To determine whether trends in opioid prescription at the state and national levels reflect increased opioid use for inpatients during the final week of life, chart reviews were conducted to record all opioid medications administered in the last week of life to 877 adult inpatients who died from natural causes between January 1, 1997 and December 31, 1999. Inpatient morphine use did not increase significantly for dying patients from 1997 to 1999. However, overall morphine use for both Oregon and the United States as measured by ARCOS data increased significantly. Comparisons revealed no significant difference between linear trends for Oregon and U.S. morphine use, but both were significantly greater than the dying inpatients. This pattern was also found for all other opioids. These findings suggest that ARCOS data do not necessarily provide information about opioid use for specific subpopulations of patients and raise questions about the meaning of observed increases in ARCOS data.

PMID: 15000781 [PubMed - indexed for MEDLINE]

65: J Palliat Med. 2004 Feb;7(1):9-17.

Predictors of site of death of end-of-life patients: the importance of specificity in advance directives.

Pekmezaris R, Breuer L, Zaballero A, Wolf-Klein G, Jadoon E, D'Olimpio JT, Guzik H, Foley CJ, Weiner J, Chan S.

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Despite the compelling reasons for advance directives and their endorsement by the public and medical professions, little is known about their actual use and impact on site of death. This study was conducted to examine the role of advance directives and other "drivers" of hospitalization of the long-term care end-of-life patient. The medical records of 100 deceased consecutive nursing home residents, stratified by site of death (skilled nursing facility or acute care hospital), were reviewed by a team of geriatric researchers to obtain patient information in the following domains: sociodemographic, advance directives, transfer and death information, patient diagnoses at admission, discharge, and other time intervals; medication usage and signs and symptoms precipitating death. Severity of illness was assessed using the Cumulative Illness Rating Scale-G (CIRS-G). In testing for differences between patients by site of death, sociodemographic variables (gender, age, race, payer at discharge, cognitive capacity) did not significantly differ between the two groups of patients. Strong similarities between the groups were also found in terms of severity of illness and medication usage. Significantly higher proportions of patients dying in the nursing home had specific advance directives (do not resuscitate, do not intubate, do not artificially feed, do

not hydrate, and do not hospitalize), as opposed to those dying in the hospital. The findings of this study demonstrate the impact of the explicit advance directive on the decision to transfer the patient to the acute care setting at the end of life.

PMID: 15000779 [PubMed - indexed for MEDLINE]

66: J Rural Health. 2004 Spring;20(2):131-5.

Urban/rural differences in decision making and the use of advance directives among nursing home residents at admission.

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CONTEXT: Advance directives promote patient autonomy and encourage greater awareness of final care options while reducing physician and family uncertainty regarding patient preferences. PURPOSE: To investigate differences in decision making authority and the use of advance directives among nursing home residents admitted from urban and rural areas. METHODS: A total of 551,208 admission assessments in the Minimum Data Set were analyzed for all residents admitted to a nursing facility in 2001. Using the Rural Urban Commuting Areas (RUCA) methodology and ZIP code of primary residence before admission, these residents were classified into 4 urban/rural areas. FINDINGS: Residents from rural areas were significantly more likely to have executed a durable power of attorney for health care or for financial decisions than residents admitted from the other areas, with the largest differences observed between residents admitted from urban and rural areas. Almost 6 residents in 10 from urban areas had no advance directives in place at admission compared with only 4 residents in 10 admitted from rural areas. CONCLUSIONS: Health providers and social workers in both rural and urban areas should advise patients about the value of advance directives.

PMID: 15085626 [PubMed - indexed for MEDLINE]

67: JAMA. 2004 May 26;291(20):2476-82.

Palliative care for patients with heart failure.

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Heart failure accounts for more hospitalizations among Medicare beneficiaries than any other condition. Its symptoms, including shortness of breath, fatigue, and edema, can be frightening and diminish quality of life. Although treatment advances have allowed patients to live longer with a better quality of life, heart failure remains a leading cause of death in the United States. Half of

heart failure patients die within 5 years of diagnosis, and for many patients, death is sudden. Given the availability of effective treatments, the prevalence of distressing symptoms, and a persistent high risk of death that may occur suddenly, physicians must simultaneously treat the underlying condition while helping patients plan for future needs and complete advance directives. Using the case of Mr R, a 74-year-old man with heart failure, we illustrate ways that physicians can address these issues to improve the care of patients with heart failure, including symptom management and discussing advance directives, prognosis, and hospice care. By combining optimal medical management with palliative care, physicians can best care for heart failure patients and their families.

Publication Types:
Case Reports

PMID: 15161899 [PubMed - indexed for MEDLINE]

68: JAMA. 2004 May 26;291(20):2432; author reply 2432.

Comment on:
JAMA. 2004 Jan 28;291(4):483-91.

The role of nurse practitioners in end-of-life care.

Demarest P.

Publication Types:
Comment
Letter

PMID: 15161891 [PubMed - indexed for MEDLINE]

69: Manag Care Interface. 2004 Apr;17(4):28-34.

Comment in:
Manag Care Interface. 2004 Apr;17(4):26-7.

Opioid use and health care charges at the end of life in patients with metastatic cancer.

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Opioid use and health care charges during the final year of life in patients with metastatic cancer who received controlled-release oxycodone (CRO), transdermal fentanyl (TF), or controlled-release morphine sulfate (CRM) were examined in the following study. A total of 704 patients were identified who met study entry criteria; CRO, TF, or CRM was the first-received long-acting opioid (LAO) during the last year of life for 36% (N = 250), 29% (N = 203), and 36% (N = 251) of study subjects, respectively. On average, patients initiated LAO therapy three to four months before death. One-half of patients received less

than 60 days of LAO therapy. Mean total health care charges in the final year of life were dollars 84,572 for patients receiving CRO, dollars 90,935 for patients receiving TF, and dollars 76,446 for patients receiving CRM. Patients receiving TF started LAO therapy closer to their date of death, and had significantly higher hospitalization charges than did patients receiving CRO and CRM.

PMID: 15108758 [PubMed - indexed for MEDLINE]

70: Manag Care Interface. 2004 Apr;17(4):26-7.

Comment on:

Manag Care Interface. 2004 Apr;17(4):28-34.

Evaluating end-of-life opioid use in managed care plans.

Giaquinta D.

Department of Pharmacy Practice.

Publication Types:

Comment

Evaluation Studies

PMID: 15108757 [PubMed - indexed for MEDLINE]

71: Med Care. 2004 May;42(5):423-31.

Comment in:

Med Care. 2004 May;42(5):406-7.

Quality of death: assessing the importance placed on end-of-life treatment in the intensive-care unit.

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CONTEXT: The value of good end-of-life (EOL) care could be underestimated if its effects are assessed using the standard metric of quality-adjusted survival, especially if the time horizon is limited to the duration of the EOL care. This issue is particularly problematic in the intensive-care unit (ICU) where death is frequent, care is difficult, and costs are high. OBJECTIVES: The objectives of this study were to test whether people would trade healthy life expectancy for better EOL care, to understand how much life expectancy they would trade relative to domains of good care, and to determine the association of respondent characteristics to time traded. DESIGN AND SUBJECTS: We used a computerized survey instrument describing hypothetical patient experiences in the ICU used to assess attitudes of a general population sample (n = 104) recruited in Pittsburgh, Pennsylvania. MEASURES: We used life expectancy traded (from a baseline of 80 healthy years followed by a 1-month fatal ICU stay) for improving

ICU care in 4 domains: pain and discomfort, daily surroundings, treatment decisions, and family support. RESULTS: Three fourths of respondents (n = 78) were prepared to shorten healthy life for better EOL care. Median time traded in individual domains ranged from 7.2 to 7.7 months overall and 9.6 to 11.4 months when restricted to those willing to trade. Median time traded for improvement in all domains was 8.3 months overall and 24.0 months by those willing to trade. In multivariable analyses, respondents who were older, nonwhite, or had children traded significantly less time, whereas those who did not perceive the ICU to be a caring environment traded more time. CONCLUSIONS: Good EOL care is highly valued, both in terms of medical and nonmedical domains, as suggested by previous work and confirmed by our data showing respondents trading quantities of healthy life several times longer than the duration of the EOL period itself. The considerable interperson variation highlights the importance of soliciting individual preferences about EOL care.

PMID: 15083102 [PubMed - indexed for MEDLINE]

72: Med Care. 2004 May;42(5):406-7.

Comment on:

Med Care. 2004 May;42(5):423-31.

A death worth dying for.

Ward NS, Teno J.

Publication Types:

Comment

Editorial

PMID: 15083099 [PubMed - indexed for MEDLINE]

73: Med Econ. 2004 Apr 9;81(7):27-30.

How to discuss end-of-life care. Here's a guide to making advance care planning a part of your practice.

Guglielmo WJ.

PMID: 15124296 [PubMed - indexed for MEDLINE]

74: Medsurg Nurs. 2004 Apr;13(2):87-90.

Ethical guidelines for assisting patients with end-of-life decision making.

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The medical-surgical nurse must be prepared to care for patients at the end of life as they face a multitude of complex issues surrounding physical, psychological, and spiritual needs. End-of-life care must not only control symptoms, but also address the social, psychological, and spiritual needs of the patient. By using a decision framework, the nurse will be better prepared to assist patients in exploring options for end-of-life care.

PMID: 15119420 [PubMed - indexed for MEDLINE]

75: Medsurg Nurs. 2004 Apr;13(2):74.

A commitment to compassion at the end of life.

Roberts D.

Publication Types:
Editorial

PMID: 15119417 [PubMed - indexed for MEDLINE]

76: Minn Med. 2004 Jan;87(1):42-3.

Coding palliative care.

Fox D.

Abbott Northwestern Hospital, USA.

PMID: 14977271 [PubMed - indexed for MEDLINE]

77: Minn Med. 2004 Jan;87(1):26-8.

Writing an ethical will.

Baines BK.

UCare Minnesota, USA.

PMID: 14977266 [PubMed - indexed for MEDLINE]

78: Minn Med. 2004 Jan;87(1):8.

Talking to patients about end-of-life care.

Whisnant R.

PMID: 14977261 [PubMed - indexed for MEDLINE]

79: Minn Med. 2004 Jan;87(1):6.

Minnesota excels in end-of-life care.

Whisnant R.

PMID: 14977259 [PubMed - indexed for MEDLINE]

80: N Engl J Med. 2004 May 13;350(20):2029-32.

Dying and decision making--evolution of end-of-life options.

Quill TE.

University of Rochester School of Medicine, Rochester, NY, USA.

PMID: 15141040 [PubMed - indexed for MEDLINE]

81: Nurs Forum. 2004 Jan-Mar;39(1):34-6.

The longest minute.

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PMID: 15098325 [PubMed - indexed for MEDLINE]

82: Nurs Stand. 2004 Mar 24-30;18(28):18-9.

The final choice.

Gooding L.

PMID: 15069743 [PubMed - indexed for MEDLINE]

83: Palliat Med. 2004 Mar;18(2):87-92.

A randomized controlled trial of aromatherapy massage in a hospice setting.

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Research suggests that patients with cancer, particularly in the palliative care setting, are increasingly using aromatherapy and massage. There is good evidence

that these therapies may be helpful for anxiety reduction for short periods, but few studies have looked at the longer term effects. This study was designed to compare the effects of four-week courses of aromatherapy massage and massage alone on physical and psychological symptoms in patients with advanced cancer. Forty-two patients were randomly allocated to receive weekly massages with lavender essential oil and an inert carrier oil (aromatherapy group), an inert carrier oil only (massage group) or no intervention. Outcome measures included a Visual Analogue Scale (VAS) of pain intensity, the Verran and Snyder-Halpern (VSH) sleep scale, the Hospital Anxiety and Depression (HAD) scale and the Rotterdam Symptom Checklist (RSCL). We were unable to demonstrate any significant long-term benefits of aromatherapy or massage in terms of improving pain control, anxiety or quality of life. However, sleep scores improved significantly in both the massage and the combined massage (aromatherapy and massage) groups. There were also statistically significant reductions in depression scores in the massage group. In this study of patients with advanced cancer, the addition of lavender essential oil did not appear to increase the beneficial effects of massage. Our results do suggest, however, that patients with high levels of psychological distress respond best to these therapies.

Publication Types:

Clinical Trial

Randomized Controlled Trial

PMID: 15046404 [PubMed - indexed for MEDLINE]

84: Pharmacoepidemiol Drug Saf. 2004 Feb;13(2):113-5.

The use of drugs to hasten death.

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PMID: 14998073 [PubMed - indexed for MEDLINE]

85: Pharmacoepidemiol Drug Saf. 2004 Feb;13(2):89-95.

Drugs used for euthanasia in Flanders, Belgium.

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PURPOSE: Our aim was to describe and assess the medicinal products and doses used for euthanasia in a series of cases, identified within an epidemiological death certificate study in Belgium, where euthanasia was until recently legally forbidden and where guidelines for euthanasia are not available. **METHODS:** In a random sample of the deaths in 1998 in Belgium, the physicians who signed the death certificates were identified and sent an anonymous mail questionnaire. The questionnaires of the deaths classified as euthanasia cases were reviewed by a

multi-disciplinary panel. RESULTS: A total of 22 among 1925 questionnaires pertained to voluntary euthanasia. In 17 cases, detailed information on the euthanatics (medicinal substances used for euthanasia) used was provided. Opioids were used in 13 cases (in 7 as a single drug). Time between last dose and expiry ranged from 4 to 900 min. The panel judged that only in 4 cases effective euthanatics were used. CONCLUSIONS: In the end-of-life decision cases perceived by Belgian physicians as euthanasia, pharmacological practices were disparate, although dominated by the use of morphine, in the very late phase of dying, in doses which were unlikely to be lethal. Most physicians clandestinely engaging in euthanasia in Belgium seemed unaware of procedures for guaranteeing a quick, mild and certain death. Information on the pharmacological aspects of euthanasia should be included in the medical curriculum and continuing medical education, at least in countries with a legal framework permitting euthanasia under specified conditions.

PMID: 14998070 [PubMed - indexed for MEDLINE]

86: Rep Med Guidel Outcomes Res. 2004 Apr 30;15(9):1-2, 5.

End-of-life care varies significantly even among top hospitals.

Rollins G.

Publication Types:
News

PMID: 15146845 [PubMed - indexed for MEDLINE]

87: Soc Sci Med. 2004 Aug;59(4):775-85.

Physician commitment in end of life care-perspectives from New Zealand and the Netherlands.

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A social constructionist approach is taken to analyse the accounts of experiences of doctors who have provided end of life care, comprising five Dutch doctors and six New Zealand doctors who had not provided physician-assisted death, and five Dutch doctors who had. A core theme of 'commitment' to the patient crossed all interviews and when a request for assisted death was received this theme altered and evolved differently between the groups. All respondents reacted by exploring reasons for the request and offering palliative care. When the request persisted, those who had provided euthanasia entered into a 'contractual commitment', constructing another "vulnerable" self in the negotiations that invited the sympathy of the hearer. This evolved to 'sacrificial commitment' when the physician provided euthanasia despite negative personal psychological effects. Constructing a self who is willing to sacrifice personal comfort to relieve the suffering of another is useful in silencing criticism of actions. The two groups who had not provided euthanasia,

intensified their efforts to find an alternative to assisted death in a 'pledged commitment' to the patient, constructing themselves as deeply committed to the patient in an intimate struggle to meet his/her need. While New Zealand doctors denied that euthanasia had ever been an option, some Dutch doctors evolved their commitment to 'potential sacrificial commitment', constructing an open-minded and accepting self, willing to consider euthanasia despite fears of negative personal consequences. The construction of alternative 'selves' in accounts is useful in inviting sympathy and silencing potential criticism of actions that may be construed negatively (because the patient was assisted to die, or because assistance to die was refused).

PMID: 15177834 [PubMed - in process]

88: Stroke. 2004 May;35(5):1130-4. Epub 2004 Mar 25.

Hospital usage of early do-not-resuscitate orders and outcome after intracerebral hemorrhage.

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BACKGROUND AND PURPOSE: Do-not-resuscitate (DNR) orders are commonly used after

severe stroke. We hypothesized that there is significant variability in how these orders are applied after intracerebral hemorrhage and that this influences outcome. **METHODS:** From a database of all admissions to nonfederal hospitals in California, discharge abstracts were obtained for all patients with a primary diagnosis of intracerebral hemorrhage who were admitted through the emergency department during 1999 and 2000. Characteristics included whether DNR orders were written within the first 24 hours of hospitalization. Case-mix-adjusted hospital DNR use was calculated for each hospital by comparing the actual number of DNR cases with the number predicted from a multivariable model. Outcome (in-hospital death) was evaluated in a separate multivariable model adjusted for individual and hospital characteristics. **RESULTS:** A total of 8233 patients were treated in 234 hospitals. The percentage of patients with DNR orders varied from 0% to 70% across hospitals. Being treated in a hospital that used DNR orders 10% more often than another hospital with a similar case mix increased a patient's odds of dying during hospitalization by 13% ($P < 0.001$). Patients treated in the quartile of hospitals with the highest adjusted DNR use were more likely to die, and this was not just because of individual patient DNR status. **CONCLUSIONS:** In-hospital mortality after intracerebral hemorrhage is significantly influenced by the rate at which treating hospitals use DNR orders, even after adjusting for case mix. This is not due solely to individual patient DNR status, but rather some other aspect of overall care.

PMID: 15044768 [PubMed - indexed for MEDLINE]

89: Swiss Med Wkly. 2004 Feb 7;134(5-6):65-8.

Ethical principles in end-of-life decisions in different European countries.

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The majority of ICU deaths are preceded by a decision to limit treatment in some way. Decisions to withhold or withdraw treatment vary considerably depending on many factors including local practice, cultural and religious background, family and peer pressure. Here we will discuss the current situation across Europe, based on the findings from three large international studies.

Publication Types:

Review

Review, Tutorial

PMID: 15113053 [PubMed - indexed for MEDLINE]